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ABSTRACT

This paper explores the issues and possible etiologies associated with Non-Organic Failure To Thrive (NOFTT), a syndrome in which a child's weight gain deviates from an established pattern to become dramatically less than norms for age and sex. The case study of a 4-year-old named Lexis complements the literature review. Lexis remained small and displayed food refusal behavior leading to malnutrition and failure to thrive. NOFFT has been associated with lack of maternal care during infancy and lack of touch. In many cases, the mothers of NOFTT children do not recognize the problem, insisting that the child is merely small. Mothers of NOFTT children demonstrate fewer vocalizations, insensitivity to child cues, more negative emotional behavior, poor affective expression, and emotional unavailability. There is no one answer to preventing NOFTT, but maternal counseling and parenting classes are crucial to a child's recovery. Intervention should target the family as a whole. (Contains 18 references.) (SLD)

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Lexis, My Little Fairy Princess: Literature Review and Case Report on Non-Organic Failure to Thrive (NOFTT)

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My Little Fairy Princess

Through my extended family I had the pleasure of meeting my little fairy princess last summer, and took her into my care whenever possible. Let me introduce you to her. Lexis is a four year-old child who belongs to a family of large boned, strong people yet she is tiny and frail. Although she is four she is the size of a small two year old. She wears size 24 months. Yet, her facial features and her quiet intelligence tell of her true age. What is known of Lexis's history is that she was born prematurely, but has not had a medical condition that would account for her continued poor weight gain. Unfortunately, it is known that throughout her short life Lexis has been neglected by her mother .

To my understanding Lexis suffers from a syndrome known as Non-Organic Failure to Thrive. Yet, her condition has not been acknowledged or recognized. She has been labeled as disinterested in food, and it has been left at that. For Lexis and the many children who live with this erroneous misunderstanding, this paper will explore the issues and possible etiologies associated with Non-Organic Failure to Thrive.

Defining and Describing NOFTT

Non Organic Failure to Thrive is a syndrome in which a child's weight gain deviates from an established pattern of growth and becomes dramatically less than norms for age and sex (Steward & Garvin, 1997). Based on standard growth charts the NOFTT child's weight gain is below the 3rd percentile or less than 80% of ideal weight for age (Drotar, 1991). Non Organic Failure to Thrive is a significant health issue for young children, accounting for 10%-20% prevalence in ambulatory care and 1%-5% of all pediatric hospitalization (Sturm & Drotar, 1991), in which at least 80% of cases occur prior to the critical developmental period before 18 months of age (Steward & Garvin,

1997). Although the causes of NOFTT are complex and have not fully been explained, there are two identifying factors, first there is no obvious disease or medical problem to contribute to the growth failure, and second the NOFTT child always present some degree of malnutrition (Steward & Garvin, 1997).

Lexis fulfills the identifying factors in NOFTT. Without medical cause she remains in the lower 3rd percentile of weight and height for her age. In addition, she displays food refusal behavior leading to malnutrition and a failure to thrive. Although NOFTT is not fully understood it does occur frequently, and certainly can lead to both physical and psychological developmental deficits for a child like Lexis. Therefore, it is crucial for professionals and families alike to develop an understanding of the complex disorder.

A Historical Account of NOFTT

The path to healing or recovery from any condition begins with an awareness of its' existence. Although society may see NOFTT as a modern phenomenon, in actuality it has a longstanding history. One of the first stories that described a non-organic failure to thrive is the historical account of the Kasper Hauser Syndrome, also known as "psychosocial dwarfism".

According to Money (1992) Kasper Hauser, born on April 30, 1812, was said to be a son of the Prince Charles of Baden and Josephine Bonaparte's' niece. Kasper was taken away from his parents in order to protect the crown for the morganatic line, and was entrusted to the care of a game-keeper. Although Kasper lived in isolation in a small dark room, he was fed regularly and groomed occasionally. Although Kasper was given what he needed to exist he lived a life without nurturance and love, without the embrace

of his parents. When the game-keeper finally abandoned Kasper at the age of sixteen, Kasper stood 4 feet 9 inches and had a dull, almost animal like affect about him. Kasper was stabbed to death in a public park because of suspicions of his heritage. In Kasper's short life he leaves us with the evidence that growth failure may indeed be a sequel to abuse and neglect (Money, 1992).

Over 100 years ago Holt (1897) described a similar condition of infantile nutritional and growth problems in which he termed marasmus. By 1915 pediatric literature used the term failure to thrive to describe rapid weight loss, listlessness, and subsequent death in institutionalized infants (Krowchuk, 1999). During this period the mortality rate for institutionalized infants was close to 100%. Yet, until Spitz (1945) few professionals recognized the importance of adequate physical and social contact necessary for healthy development of children.

In his study of 61 foundling home infants, Spitz observed that lack of maternal care during infancy was associated with physiological symptoms such as poor food intake, disturbed sleep, poor immunilogical functioning and growth retardation (Chatoor, Ganiban, Colin, Plummer & Harmon, 1998). During the 1950's a number of cases reports were published in psychiatric literature that documented infants from intact homes who experienced depression, malnutrition, and growth failure due to feeding and interactional difficulties between the mothers and the infants (Krowchuck, 1999).

Past research has also found that lack of touch was related to some cases of failure to thrive. For instance uncontrolled studies reported cases of NOFTT infants who were never cuddled by their depressed mothers, and an "unsure handling" of NOFTT infants by their mothers, while controlled studies found less physical interaction such as kissing

and caressing, but more slapping by NOFTT mothers (Polan & Ward, 1994). In a study with newborn rat pups Schnberg et al. (1984) found that deprivation of maternal touch decreased growth hormones and important growth regulators, while heavy stroking with a brush, substituted for normal maternal licking reversed the deficits (Polan & Ward, 1994). Subsequently, recently Field et al., 1986 and Scafidi et al. (1990) demonstrated that regular supplemental stroking and stimulation of the flexion-extension of the limbs increases growth of pre-term newborn infants by at least 20%, independent of caloric intake (Polan & Ward, 1994). Clearly, there is an extensive history of evidence to substantiate the existence of NOFTT and to support a psychosocial explanation to non-organic failure to thrive. Unfortunately, Lexis carries on this legacy of growth failure due to low levels of maternal nurturance, which will be elaborated on in the next section.

Maternal Factors Related to NOFTT

Maternal contribution to the disorder of NOFTT has long been the focus of research since the acknowledgement of its' existence. Early researchers believed the primary source of the disorder was based on the inadequate mothering the child received due to psychopathology and parental incompetence (Steward & Garvin, 1997). Currently, some researchers have demonstrated that mothers of a NOFTT child have no more life stresses, psychopathology, or differences in perceived social support (Steward & Garvin, 1997).

Yet, there have been distinct differences found with NOFTT mothers when compared with mothers of healthy infants. According to various researchers NOFTT mothers were less likely to have a high school degree, perceived their own childhood as more negative, received inadequate nurturing, had more childhood stresses, were more

likely to have been abused in childhood, and continued negative adult relationships plagued with their partner's lack of involvement, abuse, increased conflict, and incarceration (Steward & Garvin, 1997). In addition, mothers of a NOFTT child perceived their condition quite differently than would be expected. Researchers have reported that mothers of a NOFTT child often perceived the child as having no problem, while some perceived the child as "bad", or physically ill, while many mothers denied any interactional etiology for the problem (Sturm & Drotar, 1991).

In Selma Fraiberg's *Ghosts in the Nursery* she set forth the idea that a mother's childhood experience will affect her ability to nurture her child. Studies of NOFTT support this idea, and have found a relationship of childhood abuse and later neglect of a child. Weston et al., (1993), found significant evidence that NOFTT mothers suffered more child abuse and more abuse in their adult relationships, than mothers of healthy infants. It has been theorized that these mothers who have experienced abuse and feel unloved may not have develop adequate self-protective or positive parenting skills, which may leave both themselves and their children to be at risk for further abuse and neglect (Weston, Colloton, Halsey, Covington, Gilbert, Sorrentino-Kelly & Renoud, 1993).

As for Lexis, it is clear that her mother is incompetent as a parent, and to those of us who know her it is clear that she suffers from some type of psychopathology. Lexis's mother continually falls victim to her substance abuse addiction. This addiction has led her neglect the nurturance of her child. In addition, she perceives Lexis as not having a problem. She simply perceives her as petite. Although Lexis's mother's childhood history is not known, she has repeatedly placed herself with abusive partners, including

Lexis's father has been incarcerated more than once, for various reasons including domestic violence.

Although a system of family and friends have been a constant safety net for Lexis and her mother, there is a crucial need for intervention that not only addresses Lexis's growth problems, but also intervention that also addresses the legacy of violence in their lives so that it no longer continues to be passed on. Both mother and child need to be cared for by warm, consistent, and supportive relationships to insure healthy growth for the child (Weston et al., 1993). Certainly, there are maternal characteristics that may be related to NOFTT, but it is clear that many factors co-exist among the possible causes, one of them being the child's own temperament.

Child Factors Related to NOFTT

The child's contribution to the NOFTT syndrome must be examined along with the other possible causes. Historically, a NOFTT child is described as behaviorally difficult, exhibiting apathy, unusual watchfulness, diminished vocalizations, lack of cuddliness, and poor feeding (Steward & Garvin, 1997; Sturm & Drotar, 1991). Similarly, recent research describes them as lethargic, passive, hypervigilent, irritable, resistant to touch, having poor feeding ability, and indifferent to separation (Steward & Garvin, 1997).

By the time a child is diagnosed with NOFTT they may have become totally unresponsive to their parents and may display highly deviant feeding behaviors such as food refusal or temper tantrums that tend to tax the mothers already tenuous child rearing abilities (Drotar, 1991). Although Lexis does not display any severe defiant behaviors, she does tend to be very passive, indifferent to separation from her mother, and does

engage in poor feeding habits and food refusal. Once again it is clear that there is no one cause for a child's infliction with NOFTT. This paper will continue to explore other correlates such as mother/child interaction and familial situations.

Mother/Child Interactional Styles Related to NOFTT

Studies have shown that a child with NOFTT is at risk for developing insecure attachment relationships, particularly disorganized relationships in which the child displays inconsistent or contradictory strategies for coping with separation and reunions with caregivers (Chatoor et al., 1998). Black et al. (1993), found that mothers of a NOFTT child were almost twice as likely to engage in a neglecting parenting style than parents of an adequately growing child. These neglectful mothers tended to terminate feedings arbitrarily, had less consistent mealtimes, and limited the child's food intake, while the child responded with food refusal and a less positive affect than a comparison child (Black, Hutcheson, Dubowitz & Berenson-Howard, 1993).

Research on mother/infant dyads found that failure to thrive was associated with less maternal responsive touch during feedings and play (Polan & Ward, 1994). Data from other mother-infant dyad research indicated that NOFTT mothers spent less time visually attending to their child during mealtime, engaged in less communication, had difficulty pacing meals and interpreting whether their child was still hungry or wanted to stop eating (Heffer & Kelley, 1994). During interaction NOFTT mothers expressed significantly more irritation and criticism toward their child, while the child was significantly less sociable, and attentive while being more fussy, and demanding as compared to controls (Heffer & Kelley, 1994).

In addition, NOFTT mothers not only interacted less often and were less affectionate with their child, but they were also more likely to use physical punishment when compared to control mothers (Heffer & Kelley, 1994). In summary, mothers of a NOFTT child demonstrate fewer vocalizations, insensitivity to child cues, more negative emotional behavior, poor affective expression and emotional unavailability. In turn, a NOFTT child demonstrates emotionless facial expression, gaze aversion, minimal smiling, and negative affect when emotions are displayed (Steward & Garvin, 1997).

Lexis's mother's neglectful style in caring for her daughter has been salient through out Lexis's short life. Beyond the emotional neglect, Lexis tends to lack appropriate clothing, and cleanliness. Fortunately, family members and friends constantly buy her what she needs and help her rid of the lice she is inflicted with because of neglect.

The opportunity to observe mother-child interaction between Lexis and her mother has only arisen once for a brief few telling moments. After being in my care for the day her mother held the car door open for Lexis. Lexis stood still, seemingly frozen to ground, and looked around confused and disoriented. Her mother responded in a sharp tone, "Lexis what is your problem?" Lexis was displaying an insecure, disorganized attachment. She seemed uncertain what to do next, freeze or flee. She reluctantly got into the vehicle. Knowing that a NOFTT child is at an elevated risk for unhealthy social interaction and attachment, caring for Lexis and then letting her go back with her mother, is one of the most difficult situations I have ever experienced.

Familial and Home Environment Factors Related to NOFTT

Steward & Garvin (1997), have reported that NOFTT is not to limited to families of lower socio-economic status, but may also include families of middle class status. Typically, families of NOFTT tend to have lack of social support, may be isolated, and have conflictual relationships among family members. Mothers of a NOFTT child reported significantly more arguments, separations and reconciliation with the child's father than mothers whose child developed normally (Drotar & Eckerle, 1989). In addition, adult males tend to be absent in a greater number of NOFTT families. NOFTT families seem to provide less intellectual stimulation, and report less involvement in cultural and intellectual activities than comparison group families (Drotar & Eckerle, 1989).

Home environments of a NOFTT child have been described as disorganized, possibly impoverished, over crowded, less cohesive with chaotic and distractive meal times (Steward & Garvin, 1997). What little is known about Lexis's home environment is that she lives in a small hotel room with her mother, brother and sometimes her father. In addition, her home environment is disorganized, unclean, and with uncertain mealtimes, if they do occur. Clearly, there are many factors that contribute to the lack of growth in Lexis's and other NOFTT children's lives.

Intervention---Tomorrow's Hope

The importance in understanding NOFTT not only lies in the detrimental influences on a child's daily life, but also in deterring possible long-term developmental deficits. A thirteen year follow up study on 177 NOFTT children found lower scores on tests of intelligence, language, reading and social maturity and that these children tended

to be shorter and display more behavioral problems than their healthy peers (Mackner, Black & Star, 1997). Research has consistently found that variables of NOFTT, such as malnutrition and insecure attachments, have adverse affects on cognitive, physical and social development. The multifaceted influences of NOFTT need to be addressed early on in a child's life in order to deter harmful life long deficits, and allow the child to reach his or her full potential.

Clearly, there is no one answer to preventing NOFTT. Given that biological, behavioral, and environmental variables that interact to produce the disorder we know as NOFTT, intervention strategies must be interdisciplinary and involve multiple participants and situations (Heffer & Kelley, 1994). Professionals need to assess each aspect of the child's life who is at risk for NOFTT. A preventative ecological approach to intervention would be most appropriate, one that addresses maternal, child, and familial variables.

Nugent & Brazleton (1989) have developed an early preventative intervention, the Neonatal Behavioral Assessment Scale (NBAS), which allows for didactic exercise in which parents learn crucial information about their newborns capacities and enables parents to understand and respond to their baby's communication cues. With this assessment clinicians elicit, describe, and interpret the newborn's behavior while guiding parents to identify caregiving techniques that can best promote their infant's development. This measure not only assists to facilitate a "match" between parent and child in the early stages, it also allows clinicians to be supportive of parents at a time when many feel isolated and vulnerable (Nugent & Brazleton, 1989). This intervention can include other family members or extended family and friends who support the

mother. NBAS can be the first step to lessening the risk for NOFTT, possibly even putting off the disorder before it occurs.

Other interventions have been successful for the child once he or she has been diagnosed with NOFTT. In a worse case scenario, this may even entail hospitalization to increase caloric intake and weight gain of the child. Very disturbed families will require close monitoring by protective services when the child is returned home (Drotar, 1991). If necessary the child may be removed from the home and placed in foster care. Trained parent volunteers in specialized foster homes have been successful in fostering catch-up growth in the child (Heffer & Kelley, 1994). In addition, when these foster parents maintained relationships with the NOFTT mothers they were effective in modeling and teaching appropriate parenting and feeding skills. Neglectful parents typically have poor social/interactional, and therefore benefit from behavioral interventions that teach and model appropriate interactional skills (Gaudin, 1993).

Maternal counseling and parenting classes are crucial aspects in a child's recovery from NOFTT. Therapy needs to address not only issues of the mother's childhood and current situation, but also the possible erroneous perceptions of her child's condition. Group approaches have also been effective for neglectful mothers by providing basic child care information, problem solving strategies, management skills and social interaction skills (Gaudin, 1993). For some mothers, like Lexis's, substance abuse treatment will be also necessary.

Intervention should also target the family as a whole, seeking to clarify family communication, reframing dysfunctional patterns, and enabling parents to assume strong leadership roles (Gaudin, 1993). In addition, professionals need to determine how the

household can be restructured to benefit the child, using home assessment scales if necessary. Finally, intervention would not be complete without a focus on treatment of the neglected child. In addition to hospitalization and foster care for a NOFTT child, there is a need for daycare programs that are specially designed to integrate therapeutic activities that provide stimulation, cultural enrichment, and development of social, cognitive, and motor skills (Gaudin, 1993).

While Lexis's mother is in a treatment center, she has been placed with a nurturing family member, has been placed on a weight gain diet, and in a preschool program to stimulate her intellectual growth. The ultimate goal for Lexis, like other NOFTT children, is to be reunited with her family. Yet, this can only occur if treatment for her mother has been successful, Lexis has established adequate weight gain, and she can be insured a healthy family situation.

Conclusion

Historically, maternal neglect has been the primary focus when addressing NOFTT. It is evident that a warm, nurturing, and involved mother is vital to the healthy development of a child. Yet, today it is recognized that the etiology of this disorder is a complex one that may involve aspects of maternal characteristics, child characteristics, problematic mother/child interactional patterns, and dysfunctional familial relationship patterns. Therefore, any intervention must explore and address any, if not all, of these possible causes.

Most importantly, because of its' potential for gross growth deficits and the risk for long term developmental delays, NOFTT needs to be more widely recognized and dealt with effectively. Recently, I have been having a recurrent dream about Lexis. She

is standing by my side, and is around ten years old. In this dream Lexis is both healthy and robust. She is no longer my little fairy princess, but a strong, energetic and vibrant individual. Let's hope through awareness and intervention that this dream comes true for both Lexis and other children of NOFTT.

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